Barriers to Good End-of-Life Care: A Physician Survey

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Abstract

Surveyed about barriers to good end-of-life care were 804 Hawaii physicians in specialties most likely to care for dying patients. Responses were received by 367 (46%). The majority attended terminally ill patients within the past year and felt that the physician should be the first to tell a patient that he/she is dying. Yet 86% identified barriers to talking about end-of-life preferences and 94% identified barriers to providing good end-of-life care. Perceived as major barriers were family conflict about the best course of action, patient/family discomfort with or fear of death, and cultural/religious beliefs of the patient or family. Since relatively few respondents supported the concepts of physician-assisted suicide (32%) or physician-assisted death (18%), the alternative is for physicians to join with other concerned entities to help overcome the attitudinal, behavioral, educational, and economic barriers to providing appropriate, humane, and compassionate care for the dying.

Introduction

Improving end-of-life care has been the topic of national and local interest. Many Americans are afraid that they "will receive more medical care and less pain relief than they want" when they are dying.[1, p.14] These fears are not unfounded. A national survey found that 47% of responding physicians acted against their conscience in providing care to the terminally ill, and were more concerned about the provision of overly burdensome treatment than about undertreatment.[1] Validating fears of the public, the SUPPORT study reported that half of the patients who died in the hospital died in moderate to severe pain.[2]

What are barriers to providing good end-of-life care? Unfortunately, there are many. Whereas most Americans want to die at home, about 60% die in hospitals and another 17% die in nursing homes.[3-5] Death in the hospital, however, often is prolonged due to pressures to use heroic and aggressive treatment that, not coincidently, generates more revenue than discussion and palliative care.[6-8] Hospice care can improve the quality of one's death, but nationally, less than 15% of in-home deaths are attended by hospice.[4] In Hawaii, about 20% of deaths occur under hospice although many of these individuals are referred to hospice in the last weeks or days before death.[9]

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Several physician-related barriers have been identified as well. First, few medical text books include information about death and dying, and few medical schools and residency programs offer distinct courses or provide mentored experiences in caring for dying patients.[10-12] The SUPPORT study documented serious shortcomings in communication between physicians and patients, and found that many physicians had no knowledge of patients' preferences at the end of life.[2] Other studies have found that physicians lack knowledge about assessing and controlling death-related symptoms such as pain and psychological distress.[1,12-14]

Most patients lack knowledge about the realities of dying and the limitations (as well as the abilities) of technology.[15] When physicians cannot communicate these realities, patients may not realize that they are on a short death trajectory or may not suspect the increasing futility of the care being offered. Finally, attitudes and practices relative to death and dying are influenced by culture and religion, and may affect the quality of care physicians provide to dying patients and their families.[16] Previous Hawaii-based studies of consumers found significant ethnic differences in willingness to talk about death, completion of advance directive, desire to die at home, and opinions regarding the use of hospice services.[9,17]

There is concern that the public's support of physician-assisted suicide (PAS) and physician-assisted death (PAD) stems from their fears about being kept alive after much functioning and intellect are gone, dying in pain, and burdening loved ones at the end of life.[12] In fact, consumer support for PAS and PAD appear to be on the increase in the United States, although support is lower among minority Americans than among Caucasian Americans.[18] A population-based consumer survey in Hawaii suggested that two-thirds of adults support PAS and PAD. However, when asked if policy efforts should be focused on improving end-of-life care, rather than on legalizing PAS, 52% agreed.[9] From the physician side, a 1996 study found that less than 30% of Hawaii doctors would agree to personally perform PAS or PAD.[19]

For several years, Hawaii has been looking at the "living and dying with dignity" issue and a governor-supported commission has called for improvement. In 1999, a statewide coalition called Kokua Mau, comprised of about 150 agencies and individuals, was funded by the Robert Wood Johnson Foundation to continue research, increase access to spiritually and culturally acceptable care at the end of life, and initiate public and professional education in order to improve care of the dying. The current survey was developed in part to assess physicians' perceptions of barriers to good end-of-life care, and it is hoped that our data can support the development of interventions which will help overcome these barriers.

Methods

Respondents

We selected respondents from a Hawaii Medical Association database that includes both members of the organization and nonmembers. We excluded retired physicians, trainees, and physicians practicing outside of the state. We included physicians in specialties most likely to be involved in the care of patients with terminal illness, such as family practice and internal medicine with all of its subspecialties (e.g., oncology, cardiology, pulmonology, geriatrics). We excluded physicians in specialties least likely to be involved in end-of-life care (e.g., dermatology, obstetrics/gynecology, psychiatry, surgery).[4,20-22] Of the 867 physicians sent questionnaires, 18 had retired, 13 had moved out of state or had no forwarding address, 26 were participating in an excluded specialty, and 6 returned empty envelopes or blank surveys. Of the remaining 804 physicians, 367 (46%) returned a completed questionnaire.

Measures

Our 19-item questionnaire was based on the literature[12,23] and pilot testing. The survey asked about: respondent characteristics (ethnicity, religion, specialty, years practicing medicine, place of practice); number of terminally ill patients cared for in the past year and their place of death; use of hospice; respondent opinion on when to begin discussions about end-of-life preferences and who should first tell a patient about a terminal condition; perceived barriers to talking about end-of-life preferences; perceived barriers to providing good end-of-life care; training in end-of-life care; knowledge of a new 1999 Hawaii law on advance directives; preferences for receiving medical information; and support of the concepts of physician-assisted suicide and physician-assisted death. Responses to questions on barriers were given on a five-point Likert scale ranging from 1=not much a barrier to 5=very much a barrier. The survey defined physician-assisted suicide as "providing a competent, dying patient who requests it with a prescription for medicine for the patient to use with the primary intention of ending his/her own life" and physician-assisted death as "giving a competent dying patient who requests it a lethal injection with the primary intention of ending the patient's life."[4]

Following approval by the University of Hawaii Human Subjects Committee, the survey was mailed to the 867 eligible physicians on June 1, 2000. Reminder postcards were mailed 2 weeks later, followed by a second questionnaire mailed to nonrespondents a month after the initial mailing. All responses received before August 15, 2000 were included in the analysis. The physicians were assured that their responses would be confidential and anonymous in the cover letter. Nonrespondents were tracked by the use of code numbers preprinted on return envelopes. When each questionnaire was returned, the researcher removed it from the envelope, logged in the code number, and then destroyed the envelope. The questionnaires were then assigned consecutive identification numbers for the purpose of data entry and analysis. We were not able to compare the characteristics of the respondents and nonrespondents, as no demographic data were available on nonrespondents.

Statistical Analysis

Responses were entered into Epi-Info, a public-domain program, and subsequently converted into SPSS-PC for statistical analysis. Means and frequencies were calculated. For the questions on barriers, we collapsed the Likert-scaled ratings into two categories: a rating of 4 or 5 was recoded as "agree" and all other responses recoded as "disagree." Differences between subgroups of physicians (e.g. by ethnicity, religion, and number of terminal patients cared for in past year) were tested using chi-square. Bivariate correlation tests were used to gauge the strength of association between selected variables.

Results

Respondent Characteristics

The characteristics of respondents based on primary specialty, ethnicity, and religion are provided in Table 1. The majority were from internal medicine (72%) or family practice (23%). To discern place of practice, we asked where they saw most of their patients; 74% reported seeing most of their patients in their private offices, 14% said HMO, 9% said hospital or long-term care facility, and 9% said clinic (11 respondents checked two response options). Ethnically, 31% were Caucasian, 26% were Japanese, 18% were Chinese, 8% were Filipino and 6% were Hawaiian. In terms of religion, 10% were Buddhist, 19% Catholic, 37% other Christian, 4% Jewish, 15% other religions, and 9% reported no formal religious affiliation. Average years in practice was 18.4 years (range 1 to 64 years). Number of terminally ill patients seen in the past year varied; 11% reported seeing none, 27% reported seeing 1 to 4, 45% reported seeing 5-14, and 17% reported seeing 15 or more terminally ill patients.

Place of Death and Use of Hospice

We asked physicians who reported seeing terminally ill patients in the past year to estimate which percentage died in various settings; averaging responses suggested that 48% of patients died in acute care, 34% at home, and 28% in nursing/care homes. Hospice care is provided in all three of these settings, and 21% of respondents reported that over half of their terminally ill patients were attended by hospice at death. Correlating years practicing medicine and percent of patients referred to hospice, we found a significantly negative relationship between the two variables, suggesting that more recently graduated physicians were referring more patients to hospice ($r = -.22$, $p < .01$). We also found a significant correlation between percent of patients dying at home and percent of dying patients attended by hospice ($r = .44$, $p < .01$). No association was found between use of hospice services and physician religion or ethnicity.

Barriers to Providing and Talking about End-of-Life Care

Almost all (95%) respondents stated that physicians should be the first to tell a patient that he/she is dying (not shown in table). When asked about the best time to approach patients regarding end-of-life preferences, 35% of respondents chose middle age, regardless of health status. Other options included greater than 65 years of age (19%), when diagnosed with serious illness (18%), when patient/family suggests it (11%), less than 6-month prognosis (9%), and clearly near death (5%).

Respondents were asked to rate the extent to which specific issues were barriers to providing good end-of-life care and talking to patients about end-of-life preferences (Table 2). The most fre-

Table 1.—Sample characteristics (n=367)

	n (%) of respondents	
Primary specialty		
IM	263	(71.7)
FP	83	(22.6)
GP	14	(3.8)
Other	7	(1.9)
Ethnicity		
Caucasian	115	(31.3)
Chinese	66	(18.0)
Filipino	28	(7.5)
Japanese	96	(25.9)
Hawaiian	21	(5.7)
Other	31	(8.4)
Missing data	10	(2.7)
Religion		
Buddhist	37	(10.1)
Catholic	69	(18.8)
Other Christian	135	(36.8)
Other religion	56	(15.3)
No religion	33	(9.0)
Missing data	37	(10.1)
Average years in practice	18.4	(range 1-64)
Place of practice		
Clinic	32	(8.7)
Private office	272	(74.1)
HMO	48	(13.7)
Acute or LTC setting	35	(9.5)
# terminally-ill patients cared for in past year		
None	37	(10.1)
1-4	96	(26.1)
5-14	162	(44.1)
15+	63	(17.2)
Missing data	9	(2.4)
Mean percent of deaths in each setting		
Home		34.3
Nursing/care home		28.4
Acute care		46.8
Percent of patients who died under hospice		
<25	174	(49.2)
25-49	61	(17.2)
50-75	50	(14.1)
>75	24	(6.8)
Missing data	45	(12.7)

quently indicated barrier in both categories was family conflict about best course of action, 71% and 60%, respectively. Next were patient/family discomfort with or fear of death (71% and 59%, respectively) and cultural/religious beliefs of patient or family (47% and 41%, respectively). Number and percent of physicians agreeing with other perceived barriers are provided in Table 2.

Training and Knowledge Questions

Overall, 57% of respondents stated that they had received training in end-of-life care in one or more settings, most frequently through Continuing Medical Education but also through medical school or residency/fellowship opportunities. Only 20 (5%) reported having attended the AMA-sponsored program EPEC (Educating Physicians in End-of-Life Care), offered several times a year in Hawaii. The most preferred way to receive information about advances in medicine and healthcare was through journals (42%), followed by 1-hour lunch meetings (33%), seminars (19.3%), internet (10.4%), and CD-Rom (6%). About two-thirds said they were familiar with the 1999 changes in Hawaii law concerning advance directives and healthcare instructions.

Table 2.—Perceived barriers to providing and talking about end-of-life care

	Providing good care n (%)	Talking about Preferences n (%)
Family conflict about best course of action	264 (71.9)	224 (60.4)
Patient/family discomfort with or fear of death	260 (70.8)	216 (58.9)
Cultural or religious beliefs of patient or family	172 (46.9)	151 (41.1)
Provider time constraint	96 (26.2)	139 (37.9)
Financial barrier		
a. Patient	133 (36.2)	
b. Provider		75 (20.4)
Provider discomfort with or fear of death	112 (30.5)	91 (24.8)
Language barrier	73 (19.9)	74 (20.2)
Lack of continuity of care across settings	97 (26.7)	NA
Lack of provider knowledge of hospice and palliative care	92 (25.1)	NA
Fear of litigation	81 (22.1)	NA
Lack of hospice and palliative care services	71 (19.3)	NA

Table 3.—EOL training, preferred way to receive information, and awareness of Hawaii's new healthcare directive law.

	n	(%)
Percent with training on EOL care	208	(56.7)
Medical school	69	(18.8)
CME	101	(27.5)
-EPEC	20	(5.4)
Residency/fellowship	79	(21.5)
Preferred way to get medical information		
Journal	154	(42.0)
1-hour lunch meetings	121	(33.0)
Seminar	71	(19.3)
Internet	38	(10.4)
CD-Rom	22	(6.0)
Awareness of Hawaii's new healthcare directive law	243	(66.2)

Support of Physician-Assisted Suicide (PAS) and Physician-Assisted Death (PAD)

Support for the concepts of PAS and PAD are shown in Table 4. Overall, 32% of respondents supported PAS (providing a competent, dying patient who requests it with a prescription for medicine for the patient to use with the primary intention of ending his/her own life) and 18% supported PAD (giving a competent dying patient who requests it a lethal injection with the primary intention of ending the patient's life).

Table 4.— Support for the concepts of physician-assisted suicide and physician-assisted death, by ethnicity/religion

	Support PAS n (%)	Support PAD n (%)
Overall N=367	116 (31.6)	65 (17.7)
Ethnicity		
Caucasian (n=115)	51 (44.3)	24 (20.9)
Chinese (n=66)	20 (30.3)	13 (19.7)
Filipino (n=28)	2 (7.1)	1 (3.6)
Hawaiian (n=21)	6 (28.6)	1 (4.8)
Japanese (n=96)	28 (29.2)	20 (20.8)
Other/Mixed (n=31)	7 (22.6)	6 (19.4)
Religion		
Buddhist (n=37)	13 (35.1)	10 (27.0)
Catholic (n=69)	15 (21.7)	9 (13.0)
Christian (n=135)	36 (26.7)	18 (13.3)
Jewish (n=13)	6 (46.2)	2 (15.4)
None (n=33)	14 (42.4)	12 (36.4)
Other (n=25)	25 (44.6)	12 (21.4)

Magnitude of support varied, however, by physician ethnicity and religion. Among ethnic groups, Caucasian respondents were the most supportive of PAS (with 44% saying "yes) and Filipinos were least supportive (with only 7% saying "yes") and this difference was significant (χ^2=25.01, p<.01). Religious differences were significant too, as Catholic and other Christian respondents were more likely to say "no" to PAS than respondents with another, or no formal, religious affiliation (χ^2=20.21, p<.05). For PAD, greatest support was seen in Caucasian and Japanese (21% in each group said "yes") and the least support was reported by Hawaiians and Filipinos (only 4-5% in each group said "yes") (χ^2=30.43, p<.01). Individuals with no formal religious affiliation were most supportive of PAD (36%) while Catholics and other Christians were least supportive (13% each) (χ^2=19.53, p<.05). No statistical differences in support of PAS and PAD were detected by physician specialty, years in practice, and number of terminally ill patients cared for in the past year.

Discussion

Our findings suggest that only a minority of Hawaii physicians support PAS (32%) and PAD (18%). Support among Hawaii physicians is similar to the national figures, albeit both nationally and locally, support varies by ethnicity (with less support among minorities) and religion (with less support among Catholics). Of interest, however, is the generally consistent gap between physicians and consumers in the magnitude of support for PAS and PAD. Nationally and locally, about two-thirds of consumers support PAD/PAS,[18,24] whereas physician support rarely exceeds 40%.[4,20-22] There are likely to be multiple reasons why physicians are less supportive of PAS/PAD than consumers. But if consumer support is being driven by consumer fear of poor end-of-life care,[12] physicians will need to join efforts to improve care for the dying.

A method for improving care is to increase physician-consumer dialogue about end-of-life preferences, and to start these discussions before a patient has a health crisis. Physicians are expected to initiate this dialogue for two reasons. First, physicians see end-of-life care as their domain. In a national study of physicians associated with the Veterans Administration system, 82% felt they should be responsible for starting discussions about end-of-life preferences[23] and, in the current survey, 95% of Hawaii physicians said that the physician should be the first to tell a patient he/she is dying. Second, consumers want their physicians to initiate this discussion, and prefer to have it initiated when they are middle-aged and not yet critically ill.[25] Unfortunately, only 35% of our respondents concurred that middle age was the preferred time to begin discussions about preferences. Fully 15% felt they should wait to discuss end-of-life preferences until the patient was close to death (6 months or less) or very near death, and another 18% would wait until the patient was diagnosed with a serious illness.

Family conflict was seen as a major barrier to talking about preferences and providing good end-of-life care. However, if preferences are discussed and a surrogate is appointed early (before a health crisis occurs), perhaps conflict can be avoided or diminished. Hawaii's 1999 advance directive law (of which only 66% of our respondents were aware) includes a fine against the physician who does not follow a patient's expressed wishes, regardless of a family's threats.[26] There will still be cases in which individuals, once ill, may change their minds about a course of action, but the new law allows new preferences to be documented and a new proxy to be appointed. Some family conflict will still occur, and physicians will need to be honest about the dying process and stress that "doing everything" will not change the final outcome and may, in fact, be burdensome and painful to the dying person.[27]

Efforts to increase physician skills in communicating with patients about end-of-life issues are already underway. Nationally, principles for care of patients at the end of life, developed in 1997 by 13 organizations including the American Medical Association (AMA) and the Joint Commission on the Accreditation of Healthcare Organizations (JCAHO), are in the process of being adapted and adopted by specialty groups.[28] The AMA has produced a continuing education program, Educating Physicians on End-of-Life Care, which is offered several times a year in Hawaii. The U.H. John A. Burns School of Medicine requires its first-year students to rotate through hospice and is incorporating more training in patient communication, end-of-life care, and bioethics into its curriculum.[29] The current survey, which found an association between recent graduation from medical school and use of hospice provides evidence for the effectiveness of early training in end-of-life care. It was also gratifying that provider discomfort with or fear of death was not perceived to be a large barrier; only 25% saw it as a barrier to talking about preferences and only 31% saw it as a barrier to providing good end-of-life care.

Even when advance directives are in place and discussions have

occurred, the literature notes that the actual decision making that precedes death is more complicated than just following documented preferences. An article presenting a "rethinking" of the SUPPORT findings lists four reasons why this is so.[30] First, patient preferences are not stable; rather they evolve as patients confront new situations and new information is received. Second, many decisions get made in the course of patient care, and it is in retrospect, usually, that a particular set of decisions is seen as pivotal in precipitating the unnecessarily painful or prolonged death. Third, for hospital-based patients, players (patients, families and physicians) tend to go along with "the program" rather than advocate for less aggressive care, and families tend to feel guilty if they do not ask for everything to be done for the dying person. Finally, the SUPPORT investigators now doubt their hypothesis that players want to, or are able to, make care decisions based on prognostic estimates and preferences of a specific patient. Rather, it is more likely that role expectations for doctors and families to do everything to save the life of the patient will prevail.

Thus, the SUPPORT investigators join with other authors to suggest that drastic improvements in end-of-life care may only occur with changes to the structure and financing of care. There is a recognition that the medical culture and the health care environment encourage heroic and aggressive treatment, and that financial incentives often motivate hospitals and doctors to provide invasive interventions to dying patients whether they want them or not, quite in contrast to the model of palliative care where patients are allowed to die in peace and with dignity.[6-8,30]

Despite this growing recognition of systems barriers to good end-of-life care, it is interesting that the top three barriers for Hawaii physicians were patient/family-related. The survey queried about several potential systems barriers. However, only 20% of physicians felt that lack of reimbursement was a barrier to talking about end-of-life preferences. In relation to providing good end-of-life care, only 36% of physicians saw a patient's financial constraints and only 22% saw fear of litigation as barriers. In the era of managed care, not surprisingly, 38% found time constraints as a barrier to talking about end-of-life preferences with patients and 26% identified that to be a significant barrier in providing good care. As patients with critical illnesses have multiple specialists caring for them, 26% found lack of continuity of care across settings as a barrier. Although the state is serviced by seven hospice organizations, 19% of respondents felt that lack of hospice and palliative care services was a significant barrier to providing good care.

Returning to the top three barriers, however, Hawaii physicians reported that patient/family discomfort with death and their cultural/religious beliefs challenged physician ability to talk about and provide end-of-life care. In fact, previous surveys of Hawaii consumers have noted significant ethnic and religious differences in willingness to talk about death, completion of advance directives, preference for place of death, desire for hospice care, and support of PAS and PAD.[9,24] Ethnic and religious differences in support of PAS and PAD were seen for physicians as well. Again, the only way to reduce these barriers is to learn more about cultural and religious beliefs in general,[16] through reading and talking with representatives of those cultures/religions, and to learn more about specific patient/family beliefs by talking to them.[27] The issue of cultural difference also raises issues for the legalization of PAS and PAD. Studies from across the country have found that support for these end-of-life options associates significantly with physician characteristics (ethnicity, religion, age, specialty) and attitudes.[4,20-22] Based on this finding, many warn that legalization of PAS and PAD will "open the door to abuses of vulnerable patients on the basis of age, poverty, mental disorders, or lack of resources for palliative care."[12-13,31]

Our study was limited by its relatively low response rate (46%), especially given the efforts taken to follow-up with nonrespondents. Other studies of physician support for PAS/PAD enjoyed response rates in the range of 60-80%.[4,13,20-22] Similarly to other authors, we were unable to test differences between respondents and nonrespondents. It is likely, however, that respondents to the Hawaii survey were more aware of and interested in palliative care approaches than nonrespondents. This is evidenced by the unexpectedly high rate in-home death reported by our respondents. Specifically, respondents said that, on average, 34% of their patients died at home and only 47% of their patients died in the hospital. Data reported by the Department of Health, in contrast, note that only 21% of deaths occur at home and that 63% occur in the hospital.

It is likely that efforts on several fronts will be required to improve care to the dying and, perhaps, reduce consumer support for physician aid in dying. Health professionals need to initiate dialogues with their patients, consumers need to discuss these issues with family members and choose surrogates, and structural changes to health care financing and standards will need to be made. Given that Hawaii physicians' top three barriers to improving end-of-life care were patient/family-related (conflict, discomfort/fear of death, cultural/religious beliefs), a good place to start is with dialogue and discussion. Educational efforts that facilitate communication must be supported.

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Medical Tidbits I...

Herb Watch

The popular herb echinacea (distant cousin of the ragweed) can produce a severe allergic reaction. Dr. Raymond Mullins (from Australia) reported to the American Academy of Allergy, Asthma and Immunology that echinacea may be responsible for hives, acute asthma or anaphylaxis...

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Blood Pressure Alert

The National Heart, Lung & Blood Institute (NHLBI) had to stop its study when one of the drugs was significantly less effective in reducing cardio-vascular disease... CARDURA (the alpha blocker dexazosin) had 25% more cardio-vascular events and patients were twice as likely to be hospitalized for heart failure...

NHLBI advises that hypertensive patients on alpha blockers (including Hytrin and Minipres) should see their physicians for alternative drugs...

Medical Tidbits II...

Acute respiratory distress syndrome usually occurs in pnemonia, but can also occur in trauma patients, eg auto accidents and patients who had complications in major surgery...

Each year, an estimated 100,000 patients of all ages develop this syndrome and about 1/2 die... A new study shows that physicians in ICU may be able to save many such patients in ICU by lowering the respirator rate...

Thomas Stewart, director of ICU at Mount Sinai, however, says, "Lowering the airway pressure may not be the best treatment for all conditions..."

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